

## A YEAR OF DIGNIFIED DEATH

SINCE THE IMPLEMENTATION date of October 27, 1997, physician-assisted suicide (PAS) has been a legal medical option for terminally-ill patients in Oregon under the terms of the Death with Dignity Act.<sup>1</sup> The law specifically requires the Health Division to collect information on the patients and physicians who take action under the law, monitor compliance with procedures spelled out in the statute and supporting rules, and publish an annual statistical report. The first such official report was recently released,\* and a paper reviewing the available data was published last month in a Boston medical journal.<sup>2</sup> This issue of the *CD Summary* presents a *Cliff Notes* version of these reports, focusing on who received prescriptions, who took the lethal medications, and what influenced those decisions.

### DIGNITY ACT REQUIREMENTS

To obtain a prescription for lethal medications in Oregon, a requesting patient must be an adult, at least 18 years old, and a resident of Oregon (specific residency requirements are not defined in the current law). The Act requires that the patient be "capable" (defined as being able to make and communicate healthcare decisions). The patient must have a terminal illness with less than 6 months to live, and the request for a lethal prescription must be voluntary.

A patient who meets these requirements must make one written and two verbal requests to his or her physician. The verbal requests must be separated by at least 15 days. The prescribing physician and a consultant physician are required to confirm the terminal diagnosis and prognosis, determine that the patient is capable and acting voluntarily, and refer the patient for counseling if either believes that the patient's judgment is impaired by a psychiatric or psychological disorder. The prescribing

physician must also inform the patient of feasible alternatives such as comfort care, hospice care, and pain control options. Patients and physicians who adhere to the requirements of the Act are protected from criminal prosecution. The law specifically prohibits euthanasia (i.e., the physician cannot directly administer the lethal medications).

### OHD'S ROLE

To fulfill its mandate, the Health Division enacted reporting rules and created reporting forms.† To be in legal compliance, physicians are required to report the writing of all prescriptions for lethal medications by either completing a set of forms (available from the OHD website) or providing copies of relevant portions of the patient's chart.<sup>3</sup> We compiled data from these physician prescription reports and from patient death certificates. To learn more about patients who participated in the Death with Dignity Act during the first year of legalized PAS, we also collected information by conducting in-depth interviews with each prescribing physician after receipt of their patient's death certificate. Each physician was first asked if their patient took the lethal medications and was then asked a series of questions about their patient's underlying illness, insurance status, and end-of-life care and concerns. Because of privacy concerns, we did not interview patients, their families, or other physicians who may have provided end-of-life care.

Because of the highly charged debates surrounding this issue, we believed it was important to provide more than just a descriptive characterization of the Death with Dignity participants. To this end, we performed two studies comparing terminally ill Oregonians who chose PAS and took their lethal medications, with Oregonians who died from similar terminal illnesses but who did not participate in the Death with Dignity Act. The comparison studies had two goals. The first was

to better understand where PAS participants fit within the spectrum of all terminally-ill patients in Oregon. The second was to try and address some of the questions and concerns surrounding this issue. Who would choose PAS and why? Would PAS be disproportionately chosen by patients who were poor, less educated, uninsured, fearful of financial ruin, or lacking in access to end-of-life care or proper pain control?

### WHY WE ASKED WHAT WE ASKED

In constructing our reporting system and comparison studies, we struggled with what specific questions and issues to address. The choice of PAS may potentially be influenced by moral, ethical, medical, or financial factors. We chose to focus on issues that government and public health might influence such as access to hospice care, palliative pain control, lack of insurance, or financial fears. We did not specifically examine the influence of moral, ethical, or religious views of the choice of PAS.

### WHAT HAPPENED IN 1998?

Details of the methods and results are available in both of the published reports.<sup>1,2</sup> Here are some of the key findings.

The Health Division received information on 23 persons who received prescriptions for lethal medications under the Death with Dignity Act in 1998 (no prescriptions were written under the Act in 1997). Of these 23 prescription recipients, 15 chose PAS and died after taking their lethal medications, 6 died from their underlying illnesses, and 2 were alive as of January 1, 1999. The 15 persons who chose PAS accounted for 5 of every 10,000 deaths in Oregon in 1998.

Patients who chose PAS were comparable to all Oregonians who died of similar underlying illnesses with respect to age, race, sex, and Portland residence. Patients who chose PAS were *not* disproportionately poor (as measured by Medicaid status), less educated, lacking in insurance coverage, lacking in access to hospice care,

\*see [www.ohd.hr.state.or.us/cdpe/chs/pas/pas.htm](http://www.ohd.hr.state.or.us/cdpe/chs/pas/pas.htm)

†Hey, we're the government, it's what we do.

fearful of intractable end of life pain, or concerned about the financial impact of their illnesses. Rather, the choice of PAS was most strongly associated with concerns about loss of autonomy and loss of control of bodily functions.

In 1998, many physicians in Oregon were unable or unwilling to participate in PAS. The physicians who did participate, by writing lethal prescriptions for patients who chose PAS, represented a wide range of specialties, ages, and years in practice.

#### STUDY LIMITATIONS

There are several limitations that should be kept in mind when considering these findings. First, the small number of patients who chose PAS in 1998 limits our ability to detect smaller differences in the characteristics of patients who chose PAS and those who did not. Second, the possibility of physician recall bias must be considered. Because of the unique nature and requirements of the Death with Dignity Act, prescribing physicians may have recalled their conversations with requesting patients in greater detail than physicians for patients in the comparison group. For that matter, the entire account could have been a cock-and-bull story. We assume, however, that physicians were their usual careful and accurate selves. Finally, the Health Division has no formal enforcement role; however, we are required to report any noncompliance with the law to the Oregon Board of Medical Examiners for further investigation.<sup>4,5</sup> Because of this obligation, we cannot detect or accurately comment on issues that may be under reported.

#### NEUTRALITY AND CONFIDENTIALITY

The Health Division's goal is to be the Switzerland of this debate. Maintaining neutrality and protecting the confidentiality of the patients and physicians who participate in the Death with Dignity Act are paramount if this reporting system, and the resulting data, are to remain legitimate. The goals of our report do not include taking sides. Rather, we are charged with collecting data and have tried to present these data objectively and within the context of some of the ongoing debates.

#### DON'T FORGET US

Again, we remind all our physician readers that prescriptions written under the Death with Dignity Act must be reported. Not only is it the law, it is the only mechanism which offers you protection from criminal prosecution and offers your patient protection from insurance companies who may wish to deny benefits because of PAS. We are charged with monitoring compliance but we are not here to be intimately involved in the interactions between you and your patients or in the decision processes that may lead to the writing of a lethal prescription. Our surveillance is ongoing and your participation (and your patient's) is held in the strictest confidence. The Death with Dignity Act, reporting rules, reporting forms, and 1998 report can be found at the Health Division's web site (*vide recto*), or can be ordered by contacting us at 503/731-4024.

#### REFERENCES

1. Death with Dignity Act; ORS 127.800-127.995.
2. Chin AE, Hedberg KH, Higginson GK, Fleming DW. Legalized physician assisted suicide in Oregon: the first year's experience. *N Engl J Med* 1999;340:577-83.

3. OAR 333-009-0010 through 333-009-0030.

4. Haley K, Tolle S. Responding to professional noncompliance. In: Haley K, Lee M. eds. *The Oregon Death with Dignity Act: A guidebook for healthcare providers*. Portland, Oregon: The Center for Ethics in Health Care, OHSU, 1998:40-41.
5. Hedberg K. Oregon Health Division reporting. In: Haley K, Lee M. eds. *The Oregon Death with Dignity Act: A guidebook for healthcare providers*. Portland, Oregon: The Center for Ethics in Health Care, OHSU, 1998:43-45.

#### Timing of Hepatitis B Shots

**W**E CONTINUE to field calls from practitioners who are uncertain about the optimum scheduling of hepatitis B immunizations, particularly for the third dose. This is increasingly an issue because of current school entry requirements. The following is not a revision—just a restatement.

- Dose 1 can be given at any age, including (indeed, preferably) on day 1 (the patient's, that is).
- Dose 2 can be given as soon as 1 month has elapsed since dose 1.
- Dose 3 can be given as soon as 2 months have elapsed since dose 2 and 4 months have elapsed since dose 1, with the caveat that infants should not get dose 3 until they are at least 6 months old. This schedule is appropriate for all ages, including Enlightenment and Bronze.

In summary, minimum dose spacing is very important, but there are no maxima. Delayed doses may result in decreased compliance (birds in the hand...), social disruption (e.g., school exclusion), and decreased protection (both from delayed benefit and, for older patients, a decreased "take" rate). The series never has to be restarted, even if it has been years since the last dose. It's the beauty of immunological memory.